

LIVING

WITH THE WAIT



DAVID B. PARKER/RENO GAZETTE-JOURNAL

Heidi Smith of Reno, seen here in early September, is dying from hepatitis C but is hoping to get a liver transplant soon.

A strong will, sense of humor keep Reno mother going after 10 years waiting for liver transplant

By Jaclyn O'Malley ■ jomalley@rgj.com

Recovering in her Oregon hospital room from a devastating miscarriage in 1980, doctors told Heidi Smith she had 15 good years left to live.

"What did that mean?" the now 58-year-old Reno mother of six recalled asking, "Fifteen good years for having a miscarriage?"

The doctors explained she contracted hepatitis through the blood transfusion just given to save her life. She

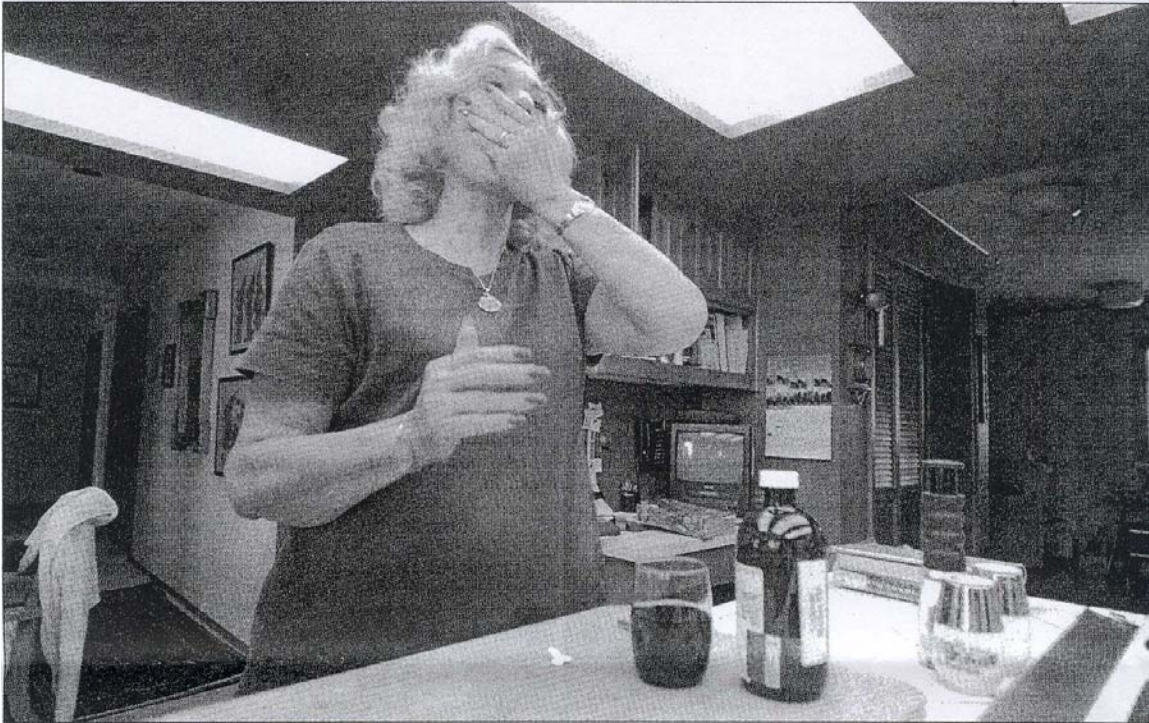
would need a liver transplant, but the doctors advised her to wait as long as she could because advancements were made in the transplant procedure every year.

"I knew I was in serious trouble," said Smith, who moved to Reno with her family two decades ago.

"A transplant?"

Smith had hepatitis C. At that time, medical officials had not discovered hepatitis C. They would not have a blood test to screen for the virus until the following decade.

'You keep cool, but sometimes you blow it. I would say, "I have six weeks to live, do you mind?" Then I didn't die, and it was embarrassing. I can read their minds. I know they're thinking, "You're still alive?"'



Transplant/ 'A walking sick person'

BY JACLYN O'MALLEY jomalley@rgj.com

Today, hepatitis C is the most common chronic blood-borne infection in the United States, with nearly 4 million infected. It's responsible for up to 12,000 deaths per year, according to the American Liver Foundation. An estimated 70 percent of those carrying the liver-destroying virus don't know they have it.

For most of the roughly 17,400 people nationwide awaiting a new liver, a transplant is their only hope for survival.

And Smith is no exception.

Twenty-five years since she was infected, and after waiting more than a decade on transplant waiting lists, Smith has been accepted by Oregon Health and Science University in Portland to receive a new liver. Her liver is ravaged, has cancerous tumors and does not function.

"This will be a surprise chapter in my life," said Smith, whose doctors told her she'd be dead by August.

"Right now, I'm just thinking about staying alive. I don't fill my head with crap about, 'I only have so many days to live.'"

Smith's experience differs from many of the 90,264 transplant candidates on the waiting list. She said that each time she is ill enough to get a transplant, her health improves and she goes to the bottom of the list. This pattern has emerged throughout the past 10 years. There is no known medical explanation for her health improvements.

"You keep cool, but sometimes you blow it," Smith said of people inquiring about her health. "I would say, 'I have six weeks to live, do you mind?' Then I didn't die, and it was embarrassing. I CAN read their minds. I know they're thinking, 'You're still alive?'"

Smith said she initially became bitter when doctors told her she had few months to live. Unlike many with liver failure, Smith's skin and eyes have not yellowed. She looks like a healthy, blue-eyed blonde, 58-year-old woman.

"I get sick and death is at my door, and then I get better," she said. "I don't look sick. I'm supposed to look, you know, like I'm sick."

Now, after several near misses, it seems she will finally get a new liver. She plans on traveling to Portland Thursday to undergo a final set of tests to make sure she is medically able to have the transplant. She said doctors have told her that if the cancerous tumor grows another centimeter, she will likely get the transplant immediately.

"She keeps going and going and part of us knows she will be there tomorrow ... but the other part once in a while hits you in the face," said her son Larry Smith, 26. "I grew up with this my entire life and it has become normal for me. I feel guilty for that."

Smith will live in Portland with Larry and his family. She will wait there for hospital officials to call when they have a matching donor.

Her situation exemplifies how humor, motivation and spirituality can help beat the odds for terminally ill patients.

It also shows how family members have to cope with a chronic, fatal illness.

"I'm the best-looking corpse in town," Smith said. "The biggest thing that has kept me alive is my sense of humor and pushing myself."

Smith, besides raising six children, is the former president and vice president of the National Federation of Republican Women, a former health insurance agent and a genealogy instructor at Truckee Meadows Community College. She has been married to Stephen Smith since 1966.

The Transplant Network and the Second Chance Foundation of Nevada feature her on their Web sites.

"Here's a lady who on one hand dines with presidents and leads a national women's organization – a lady of class, power and intelligence," said Larry Smith. "And on the other hand, I know her as my mom, who during my second-grade Halloween party was wearing a blue wig and handing out cookies. She is an amazing homemaker and mother, and is also a role model in the professional world."

Larry Smith said his mother is a fighter and doesn't let her illness interfere with her life.

"I don't know very many men or women who are able to do what she's done," he said. "I've always viewed her as Supermom and it blows me away because here she is with this illness ... but she always did more than other guys' moms."

Larry and his family will care for her following the surgery, which was a motivating factor in her decision to return to Oregon for the transplant.

Smith's insurance company promised the Oregon hospital it will fund the \$100,000 surgery and she will use community fundraisings to pay for related medical expenses. The Transplant Network in Reno estimated costs for the first year following a liver transplant on average reaches about \$313,000.

Earlier this year, Smith was supposed to receive a transplant at California Pacific Medical Center in San Francisco, but was told her insurance cap of \$100,000 was unacceptable, according to a letter from the hospital. The surgery exceeded that amount. The hospital's second concern in the letter was that she was not complying with requests for tests. Smith blames that on miscommunication and the problems associated with coordinating tests between doctors in California and Nevada.

Once she has the transplant, Smith will have months of follow-up care and expensive medications. HER LIFE expectancy is unknown.

The emotional toll

Throughout the decades of vomiting, severe bloating, insomnia, excruciating pain, rapid aging and hospitalizations, Smith never lost her sense of humor or motivation to keep active. Except for the fact she's dying, she says, "I'm the healthiest person you'll meet."

One symptom is a buildup of ammonia in her brain, which causes confusion and forgetfulness. When driving, Smith easily can get lost. She also developed diabetes, osteoporosis, has thin skin and bruises and bleeds easily.

Even though her illness was brought on from the bad blood transfusion, she said that without it, she would have died that day in 1980. She is thankful for the transfusion.

"At first you're angry, really angry," she said. "Then it's 'Why me?' I was just sitting there with all these kids to raise. I didn't do anything wrong."

"Then you cry and think, do I lay down and die or keep going?" She said. "When you live with death every day, and know you can bleed to death in your sleep ... if I thought that way, I'd be a mess."

One of Smith's doctors, Clark Harrison of Gastroenterology Consultants Ltd. in Reno, has been managing her illness for more than a decade, keeping her alive and helping her quality of life.

"She's a walking sick person," Harrison said. "But she's a strong-willed woman and has a great attitude. Fighters always do better."

In the past, Smith has testified before Nevada Assembly members to fight for organ donation awareness and easing the process. She said she will continue to fight in Nevada for these issues.

Smith also wants to regain her busy political, social and work life. She wants to see her youngest daughter, Sara, 18, grow up. Smith gave birth to Sara six years after she was infected with the virus. Sara is virus free and healthy.

"I have high hopes (the transplant) will be successful," Sara said. "Maybe I should be thinking about the worst, but I don't. She's pulled through so far ... I would be unprepared if something bad happened."

The 18-year-old recalled what her mother said to people when they asked about her health.

"I'm still above ground" was her favorite line when I was little, something I repeated when people asked me how she was doing," Sara Smith said. "What else was I supposed to tell them?"

Smith said she knows her children are afraid she could take a turn for the worse.

"She's been dying for 20-plus years, and that has to get to you after a while," Larry Smith said. "We're now at the point where I hope she still thinks it's worth it."

"They've been through the 'You're going to die' think so often that they don't believe it anymore than I do," Heidi Smith said. "You have to overcome it. Mind over matter.

"You learn how to overcome."

